

STATE OF VERMONT

HUMAN SERVICES BOARD

In re) Fair Hearing No. R-09/13-710
)
 Appeal of)

INTRODUCTION

The petitioners, parents of a now-four-year-old boy, T.L., appeal the decision by the Department for Children and Families (DCF) that he is no longer eligible for Medicaid benefits under the Disabled Children's Home Care (DCHC or "Katie Beckett") program. The issue is whether T.L. meets the disability and need-for-institutional-care criteria set forth in the regulations.

PROCEDURAL HISTORY

This matter began in September of 2013 when DCF informed the petitioners that their then three-year-old son, T.L., was no longer eligible for "Katie Beckett" Medicaid benefits. Although the petitioners timely appealed this decision to the Human Services Board, T.L.'s Medicaid benefits were initially cut off, but they were quickly restored following an initial status conference. Those benefits have continued during the pendency of this hearing.

The original notice given to the petitioners in September 2013 contained little information other than that T.L. was considered "no longer disabled" because, despite his serious medical problems, "he was still able to do most activities other children his age do." Following a request for more detail, DCF provided the petitioners with forms used by its Disability Determination Services unit (DDS) in making its decision. Those forms were not completely filled out, and focused on T.L.'s physical limitations, primarily movement and motor control. They contained no assessment of behavioral, communication, and speech/language problems which had been mentioned in the medical reports. Attempts over several weeks to get a more complete and definite statement from DDS were not successful.

The petitioners were then given leave to provide their own medical documents regarding new behavioral and language problems which had arisen for T.L. The hearing officer repeatedly encouraged them to obtain legal representation, but they declined to do so, instead generating their own medical evidence. Initially, the petitioners submitted letters from their physicians which only stated generally that those providers supported a need for payment of various therapies for T.L. At subsequent status conferences the

hearing officer carefully explained to the petitioners the eligibility standards set forth in the regulations, and the petitioners were given leave to get additional documentation from their treating sources, which they provided before the end of March 2014. DDS reviewed the new records and sent a notice dated April 12, 2014, which declined to reverse the original decision due to a lack of objective measurements regarding T.L.'s current limitations.

A hearing was held on April 22, 2014, at which time the petitioners relied on the documents from T.L.'s medical providers and a caretaker, but they asked to leave the record open to submit a report from an in-progress Individualized Education Plan (IEP) which they expected would contain some objective assessment in support of their claim. The record was left open for that document for 30 days. At the hearing the Department submitted in support of its case virtually every medical report on T.L. since the day he was born, consisting of hundreds of pages.

Following a review of the already-voluminous written evidence, the hearing officer sent the parties a memo on May 6, 2014, saying that the documents clearly showed that the child's original disabling condition had improved and that there was ample evidence of his physical limitations in the

file. The memo noted, however, that the petitioners had given the Department fair notice a year previously that T.L. was developing behavioral and language issues but that no consideration and assessment had been done regarding the severity of his problems in those areas. The only evidence appearing in the record related to these topics was a preschool teacher's subjective report which contained a number of factual errors, no objective measurements, and was based upon relatively little time spent with the child. As the record indicated that T.L. was scheduled for a complete assessment in late May of 2014 by the Vermont Department of Health, Child Development Clinic, the hearing officer ruled (over the Department's objection) that the record would be left open for another sixty days to obtain this further documentation. The 2014 IEP and the report of the Child Development Clinic, which both contain comprehensive assessments of T.L.'s array of problems, were submitted during the first week of July 2014.

SUMMARY OF THE PERTINENT EVIDENCE
AND FINDINGS OF FACT

1. Numerous records in the file document that the petitioners' son, T.L., was born at 31 weeks and had significant health problems at the beginning of his life. He

was on an oxygen ventilator, had hypoglycemia, elevated thyroid stimulating hormone, a hydrocele (hernia) that was scheduled for repair, a heart murmur, cellulitis of the hand, and neonatal retinopathy.

2. T.L. was granted "Katie Beckett" Medicaid benefits shortly after his birth, largely based upon his respiratory problems. As he was expected to improve, a review was done close to his third birthday to assess his continued eligibility. That review remains the subject of this appeal.

3. DDS initially reviewed the extant medical records as well as T.L.'s Spring 2013 Individualized Education Plan (IEP) to make its decision. The following paragraphs detail the medical information which was used as a basis for the Department's initial decision.

4. The medical records show that most of the original problems directly associated with T.L.'s premature birth had resolved, and that the only remaining original condition, hypothyroidism, was being well-controlled with medication. However, the records also show that T.L. was experiencing developmental delays and had recently been diagnosed by his neurologist as having cerebral palsy. He was prescribed orthotics (braces) to prevent him from toe-walking.

5. In the spring of 2013, when he was 36 months old, T.L. received a formal evaluation of his abilities as part of his school IEP. Several specialists, including an occupational therapist, a physical therapist, and a speech and language pathologist assessed his needs. The following paragraphs summarize their findings.

6. The physical therapist's assessment included the following:

- a. Gross Motor Skills: T.L.'s ability was equivalent to 29 months of age overall. Specifically, values on subtests were: Standing 20-33 months, walking/running 34-36 months, jumping 30-36 months, stairs 30-34 months, catching and throwing 18-20 months, balance beam 30-32 months, and riding a tricycle 32-26 months. The conclusion was that he moves safely and easily within the classroom and participates eagerly in gross motor skills in the school therapy space. It was noted that T.L. has "limited postural control and stability" and there was a concern that he walks on his toes when he is not in the braces. It was noted that he moved quickly, acted impulsively, and was in constant motion until he fatigued. Working on slowing his speed and improving his core strength were goals of the plan.
- b. Fine Motor Skills: He was found to have some weakness in his hands and immature grasp patterns when manipulating tools. Overall it was felt that he could manipulate objects adequately to manage his school needs and noted that he drank from and poured milk into a cup at school. However, his visual motor skills were "just below average." It was recommended that he could benefit from physical therapy.

7. The occupational therapist found that T.L. was cooperative, had good social-interaction and followed directions, but could be over-stimulated. She found no sensory integration concerns that interfered with functioning. She noted he had limited postural control and stability. With regard to his fine motor coordination, she noted that his grasp of writing tools was immature causing difficulty with writing control, but that he had some fine motor strengths, such as manipulating puzzles. She said he was able to use utensils and to dress himself as needed during school hours. She felt his fine motor skills were functional for school performance and age appropriate. She noted that his visual perceptual motor skills assessments were just below average and were possibly caused by unfamiliarity with the types of tasks required. It was not recommended that he receive occupational therapy as his ability to perform school tasks was not seriously impaired.

8. The speech and language pathologist tested T.L. with regard to his language skills. He found that overall his language scores were within the average range, although mostly low average. Specifically he found that T.L.'s expressive language, language context, and receptive scores were all in the average range. His language structure score

was in the borderline range. Overall, his speech was experiencing a 25 percent delay, more like 28 months, instead of 37 months. Speech language therapy was recommended.

9. With regard to his behavior, his pre-school teacher, who had spent about two hours per week with him in an early education program, filled out a specific behavioral report on him. She noted that T.L. was friendly and quite social and was able to follow directions and keep up with class activities, even though some of his classmates were older.¹ She noted that he had a "slight" problem with each of the following: understanding and participating in class discussions, providing organized oral explanations, paying attention when spoken to directly, carrying out multi-step instructions, changing from one activity to another without being disruptive, working without distracting self or others, seeking attention appropriately (but age appropriate), asking permission appropriately, following rules, using language appropriate to the situation, taking turns in a conversation, and using adequate vocabulary and grammar to express himself.

¹ This teacher made comments on the form about his medical condition which contradicted statements from his physicians and which detracted from the reliability of this opinion. However, the descriptions about his functional abilities have ultimately proven to be consistent with the observations of others who have observed and tested him. The descriptions of his medical treatment are not included in this summary as they were not made by a professional and cannot be accorded much weight.

She noted that there had been no need to employ behavior modification strategies with T.L. She checked that he had an "obvious" (but not "serious") problem with taking turns, relating experiences, and telling stories. She also noted that T.L. had a "slight" problem with moving about and manipulating objects and a more "obvious" (but not "serious") problem with demonstrating strength, coordination, and dexterity and with showing a sense of his body's location and movement in space. With regard to adaptive behavior she noted that he had "slight" problems caring for himself which was appropriate for his age. She found that he was able to exercise good judgment regarding personal safety and dangerous circumstances at school but had some difficulty maintaining attention. With regard to toilet training, she noted that he was not well toilet trained and had experienced two "accidents" at the school. Her report did say that T.L.'s parents reported that they were experiencing difficulties with him at home, including problems with dressing, bathing, teeth brushing, using the toilet, chewing objects, tantrums, loss of control, risk-taking behavior and an inability to slow himself down.

10. Based on the reports in paragraphs 4 through 9 above, DCF's Disability Determination Service (DDS) concluded

that T.L. had severe impairments, but that they neither met, nor medically or functionally equaled the listing of impairments which define disability. DDS rated T.L. as having only "less than marked" limitations in the domain called "moving about or manipulating objects." The report failed to rate T.L.'s "physical" limitations in the remaining five domains: acquiring and using information, attending and completing tasks, interacting and relating with others, caring for himself, and his general health and physical well-being. No non-physical limitations were considered or discussed. The report contained a final question asking whether there was an impairment or combination of impairments functionally equal to the listings. The question required checking one of three boxes, either "marked limitation in two domains," "extreme limitation in one domain," or "no." None of the boxes were checked. Two narratives followed, presumably from two different reviewers, and stated as follows:

#1 Current exams note clear lungs, noted to have developmental delays, has AFOs for CP, 3/17/13 exam notes 3+ DTRs, mild increased in lower extremities. Developmental Assessment at 37 mos notes FM skills at 29 months level and GM skill at 31 month level. He receives speech/language services and PT as well as OT services. Tends to walk on toes when out of AFOs but gets around very well. Significant improvement has occurred since CPD, currently limited to less than

marked degree in motor skills. Also diagnosed with hypothyroidism and is on supplement. Had evidence of hyperinsulinism during neonatal period requiring treatment but that has resolved.

#2 At CPD, child met listing 103.02E4, 5-had bronchopulmonary dysplasia on nocturnal oxygen supplements and diuretics following premature birth. Current exams note clear lungs, noted to have developmental delays, has AFOs for CP, 3/17/13 exam notes 3+ DTRs, mild increased in lower extremities. Developmental assessment at 37 mos notes FM skills at 29 months level a GM skill at 31 month level. He receives speech/language services as well as OT services. Tends to walk on toes when out of AFOs but gets around very well. Significant improvement has occurred since CPD, currently limited to less than marked degree in motor skills. Also diagnosed with hypothyroidism and is on supplement. Had evidence of hyperinsulinism during neonatal period requiring treatment but that has resolved. Motor delays would satisfy requirement for listing 111.09 pending psych assessment.

11. The petitioners were initially sent a notice saying that T.L. had been determined not to be disabled, which they appealed. Several weeks after the appeal, they were provided with the above determination along with a copy of Vermont Nursing Home Level of Care Guidelines to assist them in understanding the decision.

12. The petitioners strongly disagreed with this assessment of their son's abilities. During the course of this appeal they have provided more statements from T.L.'s treating sources, which are summarized in the following paragraphs.

13. A December 9, 2013, letter from T.L.'s primary care physician was submitted, confirming that, in the ensuing years, most of the initial life-threatening problems have resolved for T.L. and that his current principal problem is developmental delays for which he receives therapeutic services. He is being followed by a number of specialists with regard to these delays and has recently been diagnosed with cerebral palsy. The physician is also successfully treating him for hypothyroidism and gives him vitamins. She noted that his behavior and level of development required him to need a "controlled environment to maintain safety." She noted that he can quickly get out of control and put himself in a dangerous situation and has problems with "sensory overload."

14. An October 1, 2013 letter from his child development specialist stating that T.L. has cerebral palsy and will require ongoing therapies was also provided. The child development specialist says he is a safety risk and needs to be carefully monitored due to hyperactive behavior and poor impulse control. She supported T.L.'s need for a personal care attendant (which has been paid for through Medicaid) to help him to continue with his progress and to prevent regression.

15. A January 6, 2014 letter from T.L.'s neurologist stated that he is being treated for developmental delay and spasticity (cerebral palsy) and that he "needs PT/OT and speech therapy." The neurologist also stated that T.L. improves with support services.

16. The above letters were largely devoid of information required to assess the severity of T.L.'s incapacity, and when petitioner was informed of this by the hearing officer, she asked for leave to provide more detailed letters.

17. The petitioner submitted a letter dated February 26, 2014 from T.L.'s twenty-five-hour-per-week caregiver who has been with him since he was 17 months old. She wrote in detail about tantrums, difficulty dealing with change, the difficulty others have in understanding his delayed language which leads to frustration on his part, difficulty settling down and staying on task, and the need for constant redirection and change. She also talked about the help he needs to brush his hair and teeth and dress himself. She described him as a child who had difficulty with eating (gagging on food) and who was having difficulty toilet-training. She described his social interactions as awkward and inappropriate in that he "gets in the face" of people he

is talking with. She described him as active, always on the go and in need of frequent naps.

18. The petitioners offered their own statement dated February 28, 2014. They said that T.L. is at risk because he constantly puts things into his mouth (due to sensory deprivation), cannot manipulate his body easily and bumps into things or falls. His hyperactivity causes him to be in constant motion and he takes risks. Now that he is spending more time at school, they said the teachers are concerned about his problems and would be detailing them in an upcoming IEP document. They added that he is not making the progress he should due to the inconsistent availability of supportive services he needs. With regard to the six domains reviewed by DDS, the petitioners had the following comments:

- a. Acquiring and using information: This area is limited but getting better although his speech is getting worse due to a lack of speech services. They said he has trouble with routine changes and does not learn from mistakes.
- b. Attending to and completing tasks: He has a short attention span, can't follow two-step directions, and needs constant cueing, re-direction and supervision.
- c. Interacting and relation to others: He communicates by yelling and is difficult to understand. He can't always understand questions or engage in conversations with others. He has trouble understanding non-verbal cues and with focusing on things in front of him. He exhibits inappropriate

behavior with others and has tantrums when he does not get his way.

- d. Moving about and manipulating objects: He runs instead of walks, and puts everything in his mouth. He doesn't understand safety.
- e. Caring for yourself: He is not toilet trained and needs assistance with bathing, dressing, brushing his teeth, combing his hair and taking his braces off and on. He drinks from a sippy cup, cannot use utensils, and does not eat well.
- f. Health and physical well-being: He has cerebral palsy, wears braces, takes nutritional supplements, takes medication, is monitored for thyroid problems, has inconsistent sleep patterns, and gets colds often.

19. The petitioners provided their assessment detailed in paragraph 16 to each of T.L.'s medical providers and asked each to fill out their own assessments based on the criteria they had used. In response to this request, the letters in the two paragraphs were provided.

20. On March 7, 2014, T.L.'s primary care physician submitted a second letter. It is not clear whether her opinions are based on her own observations or reports from the petitioners, or both. There was nothing indicating what, if any, formal assessments had been performed to make the following ratings.

- a. T.L. has between a marked and slightly less than marked impairment in acquiring or using information due to speech impairments and he needs ongoing speech and language therapy to address this issue.

- b. T.L. has extreme limitations in attending to and completing tasks because he is in constant motion and needs redirection. He becomes overwhelmed with tasks that require more than one step.
- c. T.L. has difficulty interacting with and relating to others due to expressive language limitations, including extremely loud volume. Also he does not pick up social cues and engages in inappropriate biting.
- d. T.L. has less than a marked limitation in moving about and manipulating objects due to his clumsiness and use of AFO braces.
- e. T.L. needs assistance in caring for himself in all realms. He cannot use utensils, can't dress himself and is not toilet trained.

21. The two specialists treating T.L. agreed with the parents' statement that T.L. has a number of problems.

Again, it is not clear from their letter (dated March 10, 2014) whether these are their own observations or whether they are based on reports from T.L.'s parents or a combination of the two. It also does not appear that the specialists used any formal assessment tools to make the following statements:

- a. Acquiring and using information: A limited, but improving, ability to acquire and use information.
- b. Attending and completing tasks: He has restrictions in his ability to attend to and complete tasks due to a short attention span and a need for frequent reminders, redirection, and supervision.

- c. Interacting and relating to others: His reduced speech intelligibility and difficulty in interpreting verbal and non-verbal cues cause difficulty for him interacting and relating to others. This area is also impacted by his crying and tantrums when he feels frustrated.
- d. Moving about and manipulating objects: T.L. almost always runs and can run into things. He puts non-food items in his mouth. His ability to manipulate objects is limited and he cannot use utensils for eating.
- e. Caring for himself: T.L. has a limited ability to care for himself. He is not yet toilet trained, eats poorly and cannot dress himself or brush hair and teeth without assistance.
- f. Health and physical well-being: T.L. has CP, needs braces, takes nutritional supplements, has hypothyroidism, sleeps poorly, and engages in risky behaviors.

22. The above information was resubmitted to DDS for a re-assessment. On April 12, 2014, DDS upheld its prior decision to terminate T.L. from "Katie Beckett" Medicaid.

The decision contained the following narrative:

While the additional descriptions of T.L.'s current functional status is appreciated and acknowledged, there still is a lack of recent objective evidence in the form of speech and language evaluations, psychological exams with cognitive testing and adaptive capacities and formal developmental assessments. At the age of three, T.L. did undergo speech and language evaluations, developmental assessments and neurological exams. Although he did, at that time, present with mild cerebral palsy and a moderate speech impairment, he did not present with marked global developmental delays or a significant cognitive impairment. As such, the reported recent reduction in speech and language abilities, increase in attentional and behavioral issues and

moderate gross motor delays cannot be properly evaluated and rated under the disability determination standards without updated evaluations and assessments. The six functional domains referred to in the previous review from 2/2014 cannot be accurately rated without concrete objective evidence to go along with the subjective evidence already supplied. Katie Beckett eligibility is evaluated only after a child is found to either meet/medically equal a medical listing, or can be determined to have marked limitations in two domains or one extreme in a domain. T.L. does not meet the definition of disability based on the available evidence.

23. Subsequent to this decision, the petitioner submitted two further assessments done on T.L., one as part of an IEP for the upcoming (2014-2015) school year, and the second an evaluation by the Vermont Department of Health, Child Development Clinic.

24. The IEP was prepared over the months between March and May of 2014 for the 2014-2015 school year. The school district does not appear to have done any further formal testing on T.L. with regard to his language and speech problems and gross and fine motor skills since the 2013 IEP was prepared (see above). A new behavioral analysis was added based on a more in-depth knowledge of T.L. following a longer school week than he had the previous year. Socially and behaviorally T.L. was noted to be friendly, quite social, and to have skills in sharing, taking turns, and taking part in activities. In contrast with the year before, it was

noted that T.L. can sit and participate in class, raise his hand, and follow routines without adult support. It was also stated that T.L.'s behavior is appropriate in the classroom, and that he responds well to predictable routines and schedules. It was reported that in the classroom T.L. is able to express his wants and needs and carry on conversations with his classmates. His sentences are typically short and telegraphic. His connected speech is more difficult to understand when he tries to tell about a family event or a movie he has seen. At Show and Tell time he gives few details about his subject. At these times his volume increases which interferes with clear communication. It was noted that without braces he could be unstable and engage in toe walking, but that in braces he did better and was a fast runner. The school planned to work on slowing him down. The school acknowledged that the parents had concerns about his home behavior and about T.L. maintaining personal space and appropriately greeting others. The parents had reported that at home he has a short attention span and problems focusing which the school would work on with them.

25. On May 28, 2014, T.L. was seen at the Vermont Department of Health, Child Development Clinic by a team consisting of a developmental pediatrician, a medical social

worker, and a child psychologist. The team noted that T.L. needs ongoing therapies to deal with developmental delays. He was assessed using a number of tests and tools and the following was determined:

- a. Cognitive deficits, including language use were found to be relatively mild. He was found to be in the average range on most of his tests, particularly verbal ability, spatial ability, general conceptual ability, verbal comprehension, naming vocabulary, matrices, and pattern construction. He was considered above average in his nonverbal reasoning ability, and below average in his ability to copy. The team felt that the below average score in copying was more a function of his delayed fine motors skills than of his cognitive ability. Overall, T.L.'s thinking and reasoning skills were deemed to be in the average range, only slightly delayed and adequate for attending school.
- b. T.L.'s behavioral problems were rated on a standardized multidimensional system. His pre-school teacher and his mother were each asked to provide ratings on a number of characteristics and traits. It was noted that there was a large divergence in responses regarding his behavior largely regarding reactions and out of control behavior which the reviewers noted showed a difference between behavior at home and at school. Their own observation was that he is a "happy, lively, active, interactive, engaging, and talkative boy" who was easily distracted but easily re-directed. It was noted that he has a high level of activity and impulsivity that does create safety concerns for him. It was suggested that he be evaluated for possible ADHD. It was noted though that his social behavior and interactions at school were good and that he was making good progress.
- c. A review of his medical condition found that he still experiences problems like hypothyroidism which are "typical challenges for premature infants." It

was noted that he had "mild spastic diplegia" based on his specialists' reports and that his toe walking was becoming less frequent and did not seem to have a great impact on his daily life. He was noted to be a fast, non-stop runner.

- d. With regard to adaptation, T.L.'s problems were described as being primarily with toilet training and sleeping through the night. He was noted to have "slightly delayed" self-help skills for eating with utensils, self-dressing, and personal hygiene due to fine motor issues, inattention, impulsivity, and high activity.
- e. Socially, T.L. was observed to be socially engaged, to have spontaneously initiated conversation, to have brought and shared items of interest to him. He was found to have focused well on testing when allowed breaks for physical activity and to be cooperative and easily re-directed. He was determined to be managing "quite well" functionally.
- f. Overall, he was assessed as developing steadily with some concern that he may have ADHD with a suggestion that the school monitor for this condition as well as his ability to make judgments about safety and social interactions. It was suggested that he continue with PT, OT, and speech therapy.

26. The final report submitted by the petitioners was a letter from a behavioral analyst who has been sporadically working with T.L. for the past two years confirming that T.L.'s activity, coupled with inattention and impulsivity, cause concerns for his parents and caregivers. She also noted that T.L. becomes aggressive with his parents and siblings when frustrated, disappointed or overwhelmed. She acknowledged that T.L. is reported to be appropriate in his

school setting, but noted that there is one adult per every 3-4 children in the EEE program (pre-school), and it could be different when he faces the challenges of a regular kindergarten next year.

27. There are no significant conflicts in the above evidence with regard to the nature of T.L.'s observed physical and non-physical problems. The only point of divergence is the relative severity of these problems. Deference is due to the diagnoses of his treating sources and those diagnoses as to his current medical conditions are adopted herein as findings of fact. (See paragraphs 13, 14, 15, 20 and 21, *supra*). However, those sources have done no formal assessments of the impact of his diagnoses on his ability to function that would lend any special weight to their opinion with regard to that issue. It is also not possible to tell from their reports the extent to which their opinions are based on their own observations or reports of his parents, making their severity assessments even less reliable. The same is true of the observations of T.L.'s parents and caretaker. Although they are certainly valid observations made by people who spend the most time with T.L., they offer no insight into how T.L.'s abilities compare with other children his age--that is, how severe they are. In

addition, the observations of his personal care attendant are potentially biased, as her salary is paid through the "Katie Beckett" program.

28. In contrast, the School District professionals and the Child Development Center team have based their severity evaluations on assessment tools and protocols as well as their expertise with regard to functional norms for children of T.L.'s age. Therefore, their opinions are deemed to carry significantly more weight with regard to the *relative* severity of T.L.'s developmental delays. Their opinions as to the severity found in paragraphs 5 through 9 and 24 and 25, above, are adopted herein as findings of fact with regard to T.L.'s functional limitations.

29. In summary, T.L. is a child who is experiencing developmental delays in many areas due to his premature birth, although he physically functions very well. His developmental delays are not severe enough to prevent him from attending school and participating in all activities without the assistance of a one-on-one aide. Based on the above assessments, and the relative weight to be assigned to them, the following findings are made as to T.L.'s level of functioning.

- a. Acquiring and using information: T.L. is cognitively in the average range and is able to learn. He has strengths that are above average and his only below average skill is copying which may be related to his fine motor skill delay. His ability to understand speech is good.
- b. Ability to attend and complete tasks: T.L. is distractible and there is concern that he may have ADHD. But all those who spent time testing him or supervising him in the classroom found him to be able to focus, to follow directions, to be easily redirected and to complete tasks required of him as part of his program or testing.
- c. Interacting and relating to others: Although T.L. has some behavioral problems at home (tantrums, crying), he can control himself outside of the home and interact appropriately (although likely immaturely for his age) with peers, teachers, assessors, and therapists. He has mild speech delays (25 percent) which have caused him some difficulty always making himself understood when using longer sentences, but he is able to communicate his needs to others and initiates conversations. He is social and behaves appropriately at school.
- d. Moving about and manipulating objects: T.L. has fine motor skill delays in holding utensils and pens and pencils but has adequate grasp to take part in school activities and to pour and drink from a cup at school and to feed himself. He has about a 20 percent delay in fine motor skills for a child his age. He also has mild cerebral palsy which causes him to toe walk when he is not in braces and he has weakness in his core strength. However, while this causes some clumsiness, T.L. is able to ambulate very well, even being a fast runner. He has approximately a 15-20 percent delay in gross motor skills
- e. Caring for himself: T.L. is able to go without diapers and use the toilet on his own at school with few accidents at this point. The indications

are that he is making progress toward becoming toilet trained. He can dress himself adequately at school, although he still needs assistance with grooming, washing and teeth brushing at home. His abilities in this area are only "slightly delayed" according to the Child Development Clinic, the only entity to actually gauge this delay.

- f. Other health problems: T.L. is being treated successfully for hypothyroidism which he has had since birth. He has some difficulty sleeping but no serious health problems outside of those already discussed in a. through e. above. There is no evidence that any of his health problems, as opposed to his developmental delay, pose a serious problem for him.

30. Although his activity level and impulsivity do put him at risk and require regular supervision, there is nothing in the record indicating that T.L. might need specialized or institutional care to deal with these problems. While he does have a personal care attendant for part of the week, there are no special services currently employed by the family or the attendant to care for him in the home. He does not require a special attendant at school.

31. Other than medication for hypothyroidism, ongoing occupational, physical and speech therapy, and sporadic behavioral therapy, T.L. is not receiving any regular medical intervention. He has not been hospitalized or treated for flare ups or exacerbations of his conditions since the first year of his life.

ORDER

The decision of DCF terminating T.L. from the "Katie Beckett" Medicaid program shall be upheld.

REASONS

The DCHC (Disabled Child in Home Care) or "Katie Beckett" program provides more liberal financial eligibility criteria for Medicaid benefits to certain children with extraordinary medical needs. The goal of the program is to encourage and support families to provide home-based care for children who might otherwise be in an institution. See Fair Hearing 20,336.

To qualify for the program, the applicant must show that, he or she:

- (i) Requires the level of care provided in an institution;
- (ii) Except for income or resources, would be eligible for MABD (Medicaid for the aged, disabled or blind) if they were living in an institution.
- (iii) Can receive appropriate medical care in the community, the cost of which is no greater than the estimated cost of medical care in an appropriate institution.

(iv) is age 18 or younger

. . .

Health Benefits Eligibility and Enrollment

(HBEE) 8.05(k)(6)

As noted above, there is no indication anywhere in the voluminous medical evidence that T.L. is in need of an institutional level of care. His treating physician has indicated that he needs to be constantly supervised because he is both very active and clumsy, but there is no indication that the kind of supervision needed is significantly more than any responsible parent would provide to a young child capable of ambulation but not yet having developed the judgment to know when they are in a dangerous situation. It is true that T.L. has an attendant for 25 hours per week, but it does not appear that the attendant is providing any services to T.L. other than basic child care and supervision. Therefore, T.L. cannot be found to meet the requirement in (i) above, which is *alone* disqualifying.

However, even if T.L. *could* be found to meet the need-for-institutional-care requirement, to be found "disabled" under HBEE 8.05(k)(6)(ii), above, he must *also* show that he meets the "applicable requirements of the Social Security Administration based on information supplied by the

individual and by reports obtained from the physicians and other health care professionals who have treated the individual." HBEE 8.04 (a). For the reasons discussed below, it must be concluded that T.L. does not meet these criteria either.

The critical issue under the Social Security Regulations is whether T.L. has an impairment or combination of impairments which meet the listings for disability for children or are their functional equivalent. Children under age 18 are considered disabled if they have a medically determinable physical or mental impairment, or combination of impairments, resulting in marked and severe functional limitations, that can be expected to result in death or that have lasted or can be expected to last for at least 12 consecutive months. 20 CFR § 416.906.

The "listings" of impairments in the regulations considered disabling for children with cerebral palsy or developmental delays are as follows:

- A. Motor dysfunction meeting the requirements of 101.02 or 111.06;

Or

- B. Less severe motor dysfunction (but more than slight) and one of the following:

- 1. IQ of 70 or less; or

2. Seizure disorder, with at least one major motor seizure in the year prior to application; or
3. Significant interference with communication due to speech, hearing, or visual defect; or
4. Significant emotional disorder.

20 CFR 404, Appendix 1, Subpart P, Part B, Rule 111.07

Rule 101.2 is a motor dysfunction of all the joints due to gross anatomical deformity and is inapplicable here. Rule 111.06 provides:

Motor dysfunction (Due to any neurological disorder)
Persistent disorganization or deficit of motor function for age involving two extremities, which (despite prescribed therapy) interferes with age-appropriate major daily activities and results in disruption of

- A. Fine and gross motor movements; or
- B. Gait and station.

There is no evidence that T.L. has problems associated with his cerebral palsy and developmental delays that could be described as a "persistent dysfunction." As the Child Development Clinic said, T.L. functions "very well." His functioning is delayed but in no way is persistently disorganized or deficient to the extent that it "disrupts," as opposed to "delays," the development of his fine and gross motor movements or his gait and station. T.L.'s medical problems do not meet the listing in A.

Paragraph B. finds disability when the motor disorganization is something less, but still significant, if there are also intellectual, sensory defects, seizures or emotional problems. There is no evidence that T.L. has any of the kind of additional problems described in this section.

Since he does not meet the listings, T.L. can only be found disabled under SSI standards if he has functional limitations that equal those found in the listings. 20 CFR § 416.924(d). The "equals test" requires "two marked" or "one extreme" limitation in one or more of the six domains (described in the findings above). 20 CFR 416.926(a). "Marked" is defined in this regulation as "more than a moderate disability" which is further described as close to one-half of the chronological age. "Extreme" is beyond that point.

T.L. certainly has many limitations, but none has been described as being of such severity that he is only functioning at the same level as children half his chronological age. To the contrary, the evidence is clear that T.L. is functioning either at his age level or, with regard to his most significant delays in speech and fine motor abilities, at no less than 75 percent of the level for children his age. His delays in all areas are "less than

marked" and, therefore, are not the equivalent of the listed disability.

Inasmuch as the evidence clearly shows that T.L. fails to meet the criteria under both parts (i) and (ii) of the test cited above for "Katie Beckett" Medicaid eligibility, he cannot continue to receive benefits under that program. The petitioners, his parents, strenuously argue that T.L. has severe problems that they consider to be "disabling" for him. However, while his medical problems no doubt continue to be a challenge for him and to his parents, professionals who have measured his abilities see a child whose serious medical problems are causing him no more than slight or mild problems with functioning when compared with peers of his same age.

Although there is no question that it has been and continues to be helpful for T.L. and his parents to have an in-home aide, there is nothing even remotely indicating that T.L., without a Medicaid-provided personal care attendant, would require institutionalization to treat or control any of his behavioral problems. As DCF's decision is in accord with its regulations, the Board is bound to affirm the result. 3 V.S.A. § 3091(d), Fair Hearing Rule 1000.4D.

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